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Title: Public attitudes in Northern Ireland to linkage and sharing of health data

Background

Our objective was to assess public attitudes in Northern Ireland towards health data linkage and sharing.

Methods

The 2015 Life and Times survey included a module on 'Public understanding and views of sharing of health data, data linking, and relevant safeguards'. 1,202 respondents completed the survey with descriptive statistics and Chi squared tests used to explore their answers.

Results

GP surgeries and the NHS were most trusted to 'keep information or data that they have about people secure and use it appropriately' with smaller percentages trusting government departments and academic researchers. Trust plummeted when it came to commercial organisations and charities.

More than 2/3rds supported the sharing and linking of de-identified health data for research where there was public benefit. Sharing data with commercial organisations was seen as less acceptable, although support increased where there was potential for greater public benefit.

Nearly 1/3rd felt that data should only be shared for research if there is explicit consent, even if this means that the research is impossible. This attitude was associated with low trust in organisations.

Conclusion

Public support for data sharing is linked to trust in organisations; data protection measures and the perception of public benefit.